

THE PREVALENCE OF DIETARY RELATED COMPLEMENTARY AND ALTERNATIVE THERAPIES AND THEIR USEFULNESS AMONG CANCER PATIENTS ATTENDING THE COLNEY CANCER CENTER IN THE NORWICH AREA, UNITED KINGDOM.

Esmarie van Tonder

Thesis presented in partial fulfillment of the requirements for the degree of
Master of Nutrition at the University of Stellenbosch



Research Study Leader: Professor M.G. Herselman

Research Study Co-leader: Mrs. J. Visser

Statistician: Professor D.G. Nel

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DECLARATION

I, Esmarie van Tonder, declare that this thesis is my own original work and that all sources have been accurately reported and acknowledged, and that this document has not previously in its entirety or in part been submitted at any university in order to obtain an academic qualification.

Signature

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ABSTRACT

Background: Cancer patients have been documented to use complementary and alternative medicine (CAM) frequently, a subject that has been extensively researched. There is however a lack in the current literature of controlled studies that investigate the prevalence of CAM use among cancer patients compared to non-cancer controls.

Aim: To assess and compare the prevalence of dietary related CAM use among adult cancer patients and non-cancer controls in the Norwich area, England.

Methods: Self-administered questionnaires were used to survey cancer patients attending a comprehensive cancer centre in Norwich, and non-cancer controls attending three dental surgeries also in the Norwich area. Questions addressed patient demographics, information relating to cancer diagnosis (cancer cases only) and information on CAM use. CAM users were asked about types and duration of CAM use, reasons for use, information sources used, disclosure to health professionals, reported side effects and benefits and satisfaction with CAM therapies.

Results: Questionnaires were distributed to 132 cancer cases and 126 controls, with 98 and 96 assessable replies received from the cases and controls respectively. Overall, 47% of the cancer cases used CAM, in comparison to 53% of the control group, with no significant difference ($p=0.673$) between the two groups. Large quantities of juice, multivitamins, fish oils and glucosamine were the most popular CAM therapies among the two groups. Usage was significantly associated with the cancer site ($p=0.036$) and duration of cancer diagnosis ($p=0.050$). Only 54% of the cancer cases and 44% of the controls informed a health professional about their CAM use. The main reasons for using CAM were to boost the immune system and to improve quality of life. Reported benefits included increased optimism and hope.

Conclusions: Although CAM was commonly used by British cancer patients, there was no significant difference in comparison to the non-cancer controls. Therefore, increased awareness and knowledge of CAM use should not be limited only to those working with oncology patients, but be extended to health professionals in all patient groups.

OPSOMMING

Agtergrond: Daar is gedokumenteer dat kanker pasiënte dikwels Komplementêre en Alternatiewe Medisyne (KAM) gebruik, en dit is al intensief nagevors. Daar is egter 'n gebrek aan gekontroleerde studies wat die prevalense van KAM verbruik in kanker pasiënte en nie-kanker kontroles vergelyk.

Doelstelling: Om die prevalensie van dieetverwante KAM onder kanker pasiënte en nie-kanker kontroles in die Norwich area, Engeland te bepaal.

Metodes: Selfvoltooide vraelyste is gebruik om kanker pasiënte wat 'n omvattende kankereenheid in Norwich besoek na te vors, asook nie-kanker kontroles wat drie verskillende tandartspraktyke in die Norwich omgewing besoek het. Vrae het pasiënt demografie, kanker diagnose (slegs kankergevalle) en inligting in verband met KAM gedek. KAM verbruikers is gevra oor die tipe en tydperk van die verbruik van KAM, redes vir verbruik, bronne van inligting, meedeling aan gesondheidswerkers, nuwe-effekte en voordele, asook tevredenheid met KAM terapieë.

Resultate: Vraelyste is uitgegee aan 132 kankergevalle en 126 kontroles, waarvan 98 en 96 verwerkbare vraelyste van die gevalle en kontroles onderskeidelik teruggekry is. Sewe-en-veertig persent van die kankergevalle het KAM gebruik, in vergelyking met 53% van die kontrolegroep, met geen betekenisvolle verskil ($p=0.673$) tussen die twee groepe nie. Groot hoeveelhede sap, multivitamiene, visolies en glukosamien was die gewildste KAM in die twee groepe. Verbruik is betekenisvol geassosieer met kanker diagnose ($p=0.036$) en duurte van diagnose ($p=0.050$). Slegs 54% van die kankergevalle en 44% van die kontroles het 'n gesondheidswerker ingelig van hul gebruik van KAM terapieë. Hoofredes vir die gebruik van KAM was om die immuunsisteem en kwaliteit van lewe te verbeter. Voordele het groter optimisme en hoop ingesluit.

Gevolgtrekking: Alhoewel KAM algemeen deur Britse kanker pasiënte gebruik word, was daar geen beduidende verskil in vergelyking met die nie-kanker kontroles nie. Dus moet 'n verhoogde bewustheid en kennis van KAM nie beperk word tot diegene wat met kanker pasiënte werk nie, maar dit moet ook uitgebrei word na gesondheidswerkers in ander pasiëntgroepe.

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LIST OF ABBREVIATIONS

AFBPsS	Associate Fellow of the British Psychological Society
CAM	Complementary and alternative medicine
FDA	Food and Drug Administration
FRCP	Fellow of the Royal College of Physicians
EPA	Eicosapentaenoic acid
GCSE	General Certificate in Secondary Education
GP	General Practitioner
HMPs	Herbal medicinal products
MD	Doctor of Medicine
MRSS	Member of the Register of the Shiatsu Society
NHS	National Health Service
PhD	Doctor of Philosophy
SD	Standard deviation

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CHAPTER 1: REVIEW OF RELATED LITERATURE

1.1 Introduction

Cancer patients have been documented to use complementary and alternative medicine (CAM) frequently, but the usage rate varies widely between countries and is based on varying definitions of CAM.^{1,2} The increased interest in CAM among cancer patients may be due to limitations of conventional cancer treatment, increased media coverage of CAM, or the desire for holistic or natural treatments. It may also be used as a last resort when conventional treatment has failed. As cancer incidence increases, and survival time lengthens, the population seeking information about and access to CAM is likely to increase.³

1.2 Definition of CAM

It is necessary to distinguish between complementary and alternative medicine, despite the acronymic term commonly used.

Complementary therapies are used as adjuncts to mainstream cancer care and are supportive measures that control symptoms, enhance well-being and contribute to overall patient care. On the other hand, alternative therapies are typically promoted for use instead of mainstream treatment.⁴ It is important to note that while these therapies are used widely, often without supervision, CAM may potentially be either beneficial or detrimental to a person's health. It is thus essential that the health professional has sufficient knowledge to advise patients regarding these therapies or practices.

1.3 Prevalence of CAM Use – the Trend Worldwide

The use of CAM is increasing worldwide. A national survey in the United States demonstrated an increase in use from 33.8% to 42.1% between 1990 and 1997.⁵ In a systematic review by Ernest and Cassileth in 1998, 21 studies included adult cancer patients from 13 countries.⁶ Fifty per cent of these studies reported that up to 27% of respondents used CAM; the remaining studies found that more than 25% of respondents had tried CAM therapies. Percentages ranged from a low of 7% to a high of 64%. The average percentage use across adult studies was 31.4%.

CAM therapies are also popular among patients with chronic diseases other than cancer. Noiesen et al. (2007) has done a survey on Danish patients with allergenic contact dermatitis and found that 40% of the subjects used CAM, predominantly in combination with conventional treatment.⁷ Another study was conducted by Hilsden et al. (2003) on Canadian patients with inflammatory bowel disease and it was reported that 47% of the subjects in this study used CAM.⁸ However, no studies could be found where the use of CAM in cancer patients was compared to other diseases.

1.4 Prevalence in Britain

Fewer studies on the prevalence of CAM use were found in the United Kingdom. Downer et al. (1994) found that 16% of cancer patients used complementary therapies of which the most popular included healing, relaxation, visualization, diet, homeopathy, vitamins, herbalism and the Bristol approach⁹ (see pages 4 and 7 for further reference).

A recent study of women with breast cancer (n=714) in the South Thames NHS region of the UK found that 22% of participants had consulted a CAM practitioner, and 33% had purchased CAM products over the counter in the previous 12 months.¹⁰ Another recent study by Harris et al. (2003) found that 49.6% of oncology patients had used at least one type of CAM in the previous 12 months at the time the study was conducted.¹¹ Usage was more frequently reported for aromatherapy/massage therapy, relaxation and vitamins/minerals or fish/vegetable extracts.

1.5 Demographics of Patients Using CAM

Virtually all studies conducted to date in cancer patients and of the general public internationally show that those patients who seek CAM tend to be better educated, of higher socio-economic status, female, married or living with a partner and younger than those that do not use CAM.^{4, 12, 13} Younger patients may be more likely to use CAM as they are more mobile than older people, and therefore have greater access

to complementary services. They may also be more motivated to take extra steps (i.e. CAM services) to try and regain health. Additionally younger patients may be more likely to have prior experience acting assertively in relation to systems of authority, due to societal changes over the past several decades.¹⁴ Patients of higher socio-economic status may also be more likely to use CAM, as they have more resources for additional services.¹⁴ Similarly, many married patients or those living with a partner have a second income for the household and could therefore also have more resources available for additional services such as CAM.

1.6 Different Types of CAM Used

1.6.1 Diets commonly used among cancer patients

More than 40 different cancer diets have been claimed to prevent and/or treat cancer. These diets typically emphasize avoiding meat, and many are strictly vegetarian.¹⁵ Current examples include the Macrobiotic diet, the Bristol diet and the Gerson diet.^{9,15} The Macrobiotic diet is based on the belief that cancer is caused by an imbalance of yin and yang. It is assumed that imbalances can be corrected by eating foods with either yin or yang qualities. The macrobiotic diet is composed primarily of wholegrain products (50 – 60%) and fresh vegetables (20 -40%). Meat and milk are not allowed, but small amounts of fish are permitted. Macrobiotic diets allow few fluids but they require large amounts of salt intake (about 30g/day).¹⁵ It is, however, an expensive diet to follow as it requires special foods, tapes, literature, seminars, workshops and counseling.¹⁶ The range of food choices are limited, placing people following this diet at risk for significant nutritional deficiencies.⁴ To date there is no clinical evidence to suggest that this diet prevents, alleviates or cures cancer.^{15, 16, 17}

The Bristol diet, developed at Penny Brohn Cancer Care (formerly Bristol Cancer Help Centre), is a type of complementary diet therapy. It is perhaps the best-known diet in the UK for people with cancer. The emphasis of this diet is on wholefoods; fresh fruit and vegetables; raw cereals; and organic fish, poultry and eggs. The diet stresses the avoidance of dairy produce such as milk, cheese and yoghurt, red meat,

salt, sugar and caffeine (e.g. tea and coffee) and encourages the use of organically grown produce.¹⁷ Although the Bristol diet can be nutritionally sound, nutritional deficiencies can occur if food choices are too restricted. This may also be an expensive diet to follow as it requires all food to be organically produced. However, no published literature could be found on the possible consequences of this regime.

The Gerson diet is a vegan diet and a form of alternative medicine, and patients are expected to consume the juices of about 9kg of fruit and vegetables per day (primarily carrots and apples). The diet is often supplemented with coffee enemas. The “Gerson Institute” offers anecdotal evidence of success in its promotional literature. However, the study referred to was retrospective, its sample size was small, and about a third of the patients were lost to follow up. Bias was further introduced by use of a self-selected sample, and through the use of non-randomised controls.^{15,16,17} No study published in the peer-reviewed literature provides reasonable evidence that the Gerson therapy is effective in the treatment of cancer. However, serious infections and death from electrolyte imbalance due to the use of coffee enemas have been reported.¹⁶

1.6.2 Micronutrient supplementation

Megavitamin therapy is characterized by the use of large doses of one or more vitamins, and its use as an adjunct to current cancer therapies is continuously being explored. Many oncologists have long maintained that high dose adjunctive antioxidant vitamins are contra-indicated in patients undergoing either radiotherapy or chemotherapy, because antioxidants might reduce tumor cell kill effects by interfering with treatment induced tumoricidal free radical production. However, there is an increasing amount of data indicating that high doses of vitamin supplementation in combination with conventional therapy, may increase tumor response and improve quality of life by decreasing the toxicity of conventional treatment.^{18, 19} In fact, a recent review of the literature by Simone et al. which included 280 peer-reviewed *in vitro* and *in vivo* studies, have consistently shown that antioxidants and other micronutrients such as β -carotene (10 000–20 000IU), Vitamin A (9 000–40 000 IU), Vitamin C (500-5000mg) and Vitamin E (200 -2500 IU), selenium (387 μ g); Vitamin

D₃ (0.75mg), Vitamin K₃ (as menadione 1-3 g/m²) and glutathione (200–2500mg) as single agents or in combination) do not interfere with therapeutic modalities for cancer. It also showed that these nutrients may enhance the destructive potential of therapeutic modalities for cancer, decrease their side-effects and protect normal tissue.²⁰ Of concern, however, is the findings of an increased risk of lung cancer associated with supplementation with β -carotene. A large primary prevention trial (The Beta-Carotene and Retinol Efficacy Trial) involving supplementation with 30mg of β -carotene plus 25 000 IU of retinol, was terminated ahead of schedule during early 1996 after preliminary results showed a 28% increase in lung cancer and a 17% increase in overall deaths in the supplemented group.²¹

1.6.3 Herbal medicinal products (HMPs)

With many medicinal plants it is not possible to define the principle active constituents; the clinical effects of most HMPs are produced by more than one active compound, and in many instances the full range has not been identified. Several traditions of herbal medicine (e.g. traditional Chinese medicine, Aurveda) typically use complex, often individualized, mixtures of several medicinal herbs in one single prescription, although most modern self-prescribed HMPs consist of one single herb.¹² Few products have been formally tested for side effects or quality control (Table 1.1).⁴

Table 1.1: Examples of medicinal products for which systematic reviews and meta-analysis have been published ¹²

Common name or plant	Indication	Evidence of effectiveness
Aloe vera	Various	Poor
Artichoke	Hyperlipoproteinemia	Poor
Feverfew	Prevention of migraine	Encouraging
Ginger	Nausea and vomiting	Encouraging
Ginkgo biloba	Dementia	Good
Ginkgo biloba	Intermittent claudication	Good
Ginkgo biloba	Tinnitus	Good
Ginseng	Various	Poor
Horse chestnut	Chronic venous insufficiency	Good
Kava	Anxiety	Very good
Mistletoe	Cancer	Poor
Peppermint	Irritable bowel syndrome	Encouraging
St John's wort	Mild/Moderate depression	Very good
Valerian	Insomnia	Encouraging

1.6.4 Homeopathy

Homeopathy is a therapeutic method using diluted preparations or substances whose effects, when administered to healthy subjects, correspond to the manifestations of the disorder (symptoms, clinical signs, pathological states) in the individual patient.^{17, 22} The body's own healing process is believed to be stimulated by these highly diluted substances derived from plants, minerals or animals. Efficiency is unlikely to be due to the extreme dilution of the active ingredient in homeopathy.⁴ Systematic reviews and meta-analysis of homeopathy clinical trials show no definite proof that these remedies are effective for any medical condition.²²

1.6.5 Shark cartilage

Advocates of shark cartilage as a cancer therapy base their therapy on its putative antiangiogenic properties.⁴ Two glycoproteins have been isolated from the cartilage of the hammerhead shark and were reported to have strong antiangiogenic activity inhibiting tumour neovascularization, an effect which could be helpful in human

cancer therapy. However, as macromolecules are not usually absorbed by the intestinal tract, it is questionable whether these glycoproteins ever reach the bloodstream in sufficiently high concentrations. To date, no controlled clinical studies testing the efficacy of shark cartilage have been published.¹⁵

1.6.6 Coffee enemas

As part of the Gerson diet, coffee enemas are usually administered on a four-hourly basis to help relieve pain, nausea and other symptoms accompanying detoxification. Proponents claim that caffeine is absorbed in the colon, leading to vasodilatation of the liver, which in turn enhances the process of elimination of toxins. The assumptions are unproven, and there is no reliable evidence of the clinical efficiency of coffee enemas for any indication.^{15, 16}

1.6.7 Other non-dietary related CAM

Other non-dietary CAM includes acupuncture, chiropractic therapy, meditation, ozone therapy and spiritual healing. Acupuncture is the insertion of needles to stimulate acupuncture points located along meridians, which are assumed to promote the flow of Qi (life force), thereby restoring the balance needed for health.^{15,17} There is good evidence for the use of acupuncture for non-specific back pain, dental pain, migraine and nausea/vomiting. Of these conditions, only nausea and vomiting are directly relevant to cancer patients. Chiropractic therapy is based on the belief that the nervous system is the most important determinant of a person's state of health. Chiropractors employ spinal manipulation to treat symptoms such as neck and back pain. However, there is no evidence that chiropractic alleviates symptoms related specifically to cancer.¹⁵ Meditation is a general term describing treatments in which a person empties his/her mind of extraneous thought with the elevating mind to a different level and transcending in mundane concerns.^{15,17} The physiological effects of meditation are those of deep relaxation. There is evidence from controlled clinical trials suggesting that these effects can be used to control cardiovascular risk factors, chronic pain and anxiety, which could be of benefit to cancer patients.¹⁵ Ozone therapy is a treatment promoted for cancer, and includes

drawing up to 300ml of blood, expose it to a mixture of oxygen and ozone, followed by a reinfusion of this blood into the patient. Numerous reports exist of serious complications, including hepatitis and at least five fatalities have been reported.¹⁵ Spiritual healing has been defined as the direct interaction between one individual (the healer) and a patient, with the intention of improving the patient's condition or curing the illness. Treatment can occur through personal contact or through a distance. Several variations exist, including therapeutic touch, Reiki (placing of hands over certain parts of the body to rechannel energy flow and reversing illness¹⁷), faith healing and intercessory prayer. Mind-body interventions such as meditation, relaxation, self-hypnosis and yoga are considered beneficial and sound supportive care.¹⁵ Good documentation exists for these therapies in stress reduction, symptom management, and control of some physiological reactions.^{15, 23}

1.7 Perceived Benefits and Reasons for Using CAM

As more cancer patients turn to CAM in their quest to find a cure for their illness or to better their quality of life, the need to understand their views or perceptions of CAM is of interest.²⁴ Various studies have reported that reasons for using CAM include pain relief, relaxation, enhancing treatment outcome and to help cope with the side effects of conventional medical treatment.^{11,13} Other reasons include that cancer patients value the closer relationships possible with CAM practitioners, and because they want more control over, and greater responsibility for, self-care.⁴ Another study showed that the three most important reasons for using CAM included the desire to include every available option (77%), having information that CAM had worked well for others (70%) and feeling that CAM was less harmful or more natural than conventional treatment.²⁵

In the study by Harris et al., dissatisfaction with CAM was low, although one in four patients was uncertain about the benefit of diet/supplements.¹¹

1.8 Known Drug Interactions of CAM and Toxicity/Safety

The general public tends not to be aware that herbs are dilute drugs that contain scores of different chemicals, most of which have not been documented. Their effects are not always predictable.⁴ In addition, in this unregulated industry, it is extremely difficult to guard against consumer fraud.²⁶ The potential for harm is considerable for several of the CAM treatments (e.g. coffee enemas, ozone therapy, HMPs).¹⁵ Patients undergoing active treatment should be advised to stop using herbal remedies, because some herbs cause problematic interactions with chemotherapeutic agents, sensitizations of the skin to radiation therapy, dangerous blood pressure swings, and other unwanted interactions with anaesthetics during surgery (Table 1.2). Herbs such as feverfew, garlic, ginger and ginkgo have anticoagulant effects and should be avoided by patients on coumadin, heparin, aspirin and related agents.^{4, 26} St John's Wort is a readily available over the counter herb that is commonly used to treat depression. Side effects include nausea and hypersensitivity reactions which can decrease dietary intake in an already nutritionally compromised patient.²⁶ In high doses Echinacea can lead to hypersensitivity reactions including anaphylaxis; whereas green tea can lead to side effects such as emesis, insomnia, diarrhoea and confusion.²⁶ Concerns have been raised recently about dietary antioxidants, which may interact with radiation therapy or chemotherapeutic agents.⁴ The risk of herb-drug interactions appears to be greatest for patients with kidney or liver function impairment.⁴ Unfortunately there is currently essentially no regulation by any governmental body, including the FDA, on the safety or effectiveness of herbal medications.^{4, 15, 26}

Table 1.2 Toxicity of commonly used complementary and alternative medicine (CAM) ²⁶

CAM	Toxicity
St John's Wort	Nausea, hypersensitive reactions
Ephedra alkaloids	Hypertension, tachycardia, stroke, seizures
Kava	Yellow discolorization of skin/nails, hepatic dysfunction, stupor, visual disturbances, dizziness
Echinacea	Hypersensitivity reactions (including anaphylaxis)
Saw palmetto	Diarrhea, constipation, head ache, hypertension, insomnia, nausea
Ginseng	Diarrhea, headache, hypertension, insomnia, nausea
Ginkgo	Emesis, headache
Green Tea	Emesis, insomnia, diarrhea, confusion
Hydrazine sulfate	Hepato-renal failure
Shark cartilage	Emesis, constipation, hepatitis
Laetrile	Emesis, headache, dizziness, obtundation, dermatitis
Antineoplasms	Somnolence, confusion

1.9 Reporting of CAM Use to Physicians

Patients appear increasingly willing to discuss the use of CAM therapies, especially when asked by their oncologist.⁴ In fact one study showed that the majority of subjects would welcome the opportunity to talk to their physicians about their use of these therapies.¹³ A study on women with breast cancer found that 73.8% of participants had communicated use of CAM therapies to their physicians,¹² however, another study on various types of malignancies found that only 41% of CAM users had informed their oncologist. Older patients were significantly less likely to inform oncologists than younger patients.²⁸

1.10 Patient Expectations Regarding the Use of CAM

Several studies found that cancer patients were using CAM in the hope of anti-cancer effects, some were hoping for a cure and others for control or prevention of the spread of the cancer.^{9, 27} Some expected that CAM would boost the immune system.⁷ CAM use in general is not supported by convincing data.¹⁵ This is particularly true for CAM as a cancer cure. The role of CAM as a palliative or

supportive cancer treatment might be slightly different. CAM modalities such as acupuncture and reflexology have the potential to increase well-being with little potential for harm¹⁵ Furthermore, certain antioxidants such as vitamin E and vitamin C may also be of benefit for cancer patients undergoing chemotherapy (by reducing the generation of lipid peroxides resulting from the chemotherapy) and are relatively safe to use at high doses. Antioxidants may also have an important role in patients undergoing radiotherapy by selectively inhibiting repair of radiation damage of cancer cells, whilst protecting normal tissue. The doses at which such positive effects were noticed, ranged from 200 to 2500 IU of Vitamin E per day and 500mg to 5000mg Vitamin C per day.^{19,20,29}

1.11 Motivation for this Study

To date most studies reported a high use of CAM in cancer patients. However, a major limitation of these studies is that they were not controlled; hence we do not know how cancer patients compare with other groups. It is important to assess whether oncology patients are more likely than the general public to use CAM as they are often already nutritionally compromised, and certain type of CAM use may further restrict dietary intake. To date there is only one controlled study that we are aware of where the use of CAM in cancer survivors was compared with a non-cancer population.³⁰ According to their findings CAM use was modestly higher among cancer survivors (40%) compared to the general population (36%).

In addition, is it important for the health professional working in oncology to have an idea of the types of CAM most commonly used in their area and their reasons for using CAM. This will improve patient care and enable the health care professional to advise on safe and beneficial CAM practice in a patient-centered environment.

CHAPTER TWO: METHODOLOGY

2.1 Aim of the Study

The aim of the study was to assess and compare the prevalence of dietary related complementary and alternative medicine (CAM) use among adult cancer patients at the Colney Cancer Centre and non-cancer controls, Norwich area, England.

2.2 Objectives

- 2.2.1 To identify the most common CAM used, with a special reference to diet, micronutrients and herbs.
- 2.2.2 To determine the correlation between CAM use and patient characteristics.
- 2.2.3 To determine how often patients discuss the use of CAM with health professionals.
- 2.2.4 To determine patient's reasons for CAM use.
- 2.2.5 To investigate reported perceived side effects/complications of CAM use.
- 2.2.6 To determine the perceived benefits and satisfaction of CAM use.

2.3 Null Hypothesis

There is no significant difference in dietary related CAM use between cancer patients and non-cancer controls.

2.4 Study Design

An analytical, cross-sectional study design was used. Data were collected by means of structured validated questionnaires. A quantitative approach was used throughout the data collection process.

2.5 Subjects

2.5.1 Description of the Study population

The cancer cases in this study consisted of all adult cancer outpatients attending the Colney Cancer Centre at the Norfolk and Norwich University Hospital between mid November and end of November 2006. Being the only comprehensive cancer centre in

the Norwich area offering chemotherapy, radiotherapy and surgery, the Colney Cancer Centre drains patients from a mixture of socio-economic backgrounds. Although the majority of patients attending the Colney Cancer Centre are NHS (National Health Service) patients, private patients also make use of the centre's specialist treatments.

Since cancer patients, who are usually older than the general population, often present with co-morbid chronic conditions such as hypertension, it was decided to use a control group with similar co-morbidities instead of using healthy controls (i.e. comparable in all aspects other than cancer). This would allow for the assessment of the effect of cancer *per se* on the use of CAM. The investigators therefore decided not to select the controls from Norfolk and Norwich Hospital since such patients would generally be suffering from illness, resulting in a control group with a higher burden of chronic disease compared to the cancer group. The controls were therefore recruited from dental surgeries in the area who are visited by a better mix of healthy people and those suffering from chronic disease. The controls consisted of all adult non-cancer patients waiting in the reception areas of a convenience sample of three pre-selected dental surgeries between mid January and end of January 2007. In order to allow for a range of socio-economic backgrounds, it was decided to include two NHS dental surgeries and one private dental surgery. Two of the surgeries were located in Norwich's city centre (1 NHS and 1 private), while the third surgery (NHS) was in Attleborough, a small rural town within the immediate surroundings of Norwich. The chosen dental surgeries were:

1. Orford Hill Dental Surgery (NHS), Norwich
2. Corner House Dental Surgery (Private), Norwich
3. Church Street Dental Surgery (NHS), Attleborough

2.5.2 Sample size

To determine the sample size required for the study, the average number of patients that attended the Colney Cancer Centre during the period of April 2004 until March 2005 was calculated at 1944 patients. This information was provided by the Information Technology Department of the hospital and included the total number of patients

(excluding follow-up appointments) of all the different oncology and haematology out-patient clinics, as well as those who came for chemotherapy and radiotherapy treatments. A sample size of 92 cancer patients (cases) was calculated to achieve a 10% precision at a 95% confidence interval. This level of precision was considered acceptable to allow for a tolerable burden for participants in a fragile oncology setting, as was requested by the Norfolk Research Ethics Committee. The controls were to be of similar size and matched for age and gender. It was decided not to match the controls for ethnicity, as only 6% of the Norwich population consists of ethnic minorities (of which 3% is non-white) and should therefore not have a significant impact on the results.³¹ Furthermore, it would have complicated the matching process, as two other variables were already being matched for.

2.5.3 Inclusion criteria

2.5.3.1 Cancer cases

Any diagnosis of cancer was included among cases.

Patients had to be English speaking and at least 18 years of age.

Patients had to be able to read and write English.

2.5.3.2 Non-cancer controls

Subjects had to be English speaking and at least 18 years of age.

Subjects had to be able to read and write English.

2.5.4 Exclusion criteria

2.5.4.1 Cancer cases

Patients not willing to participate in the study.

Patients younger than 18 years of age.

Patients that took part in the pilot study.

2.5.4.2 Non-cancer controls

Patients not willing to participate in the study.

Patients younger than 18 years of age.

Patients with cancer

Patients that formed part of the pilot study

2.6 Methods of Data Collection

2.6.1 Selection of cases and controls

2.6.1.1 Cancer cases

Data collection of the cancer cases took place from mid November until the end of November 2006. This arm of the study was conducted twice a week over a period of three weeks. It was agreed with the out-patients manager to limit data collection to only twice a week, as there were issues with understaffing, which resulted in long queues at the reception desk where data collection was taking place. All the oncology out-patients share the same waiting room and reports to the main reception desk. To maximise the likelihood that all tumour sites were included, clinics from each day of the week (each weekday represent specific tumour related clinics) were included in equal proportions over the three week period as follows: week one included the Monday and Wednesday clinics; week 2 included the Tuesday and Thursday clinics, and week 3 included the Friday clinics. Posters were displayed in the waiting area of the Colney Cancer Centre to inform patients of the study in progress. Systematic sampling was used, whereby the volunteer asked every third patient if they would like to participate in the study as they reported to the receptionist. For logistical reasons it was decided to use systematic sampling (as opposed to randomised sampling), in order to cause minimum disruption to an already understaffed and overcrowded reception area. A letter explaining the purpose of the study and assuring confidentiality (addendum 1) was offered to patients at the same time, together with an anonymous questionnaire (addendum 2). Consent was assumed if a patient agreed to take part in the study, which is standard practice in the case of anonymous self-administered questionnaires where participants complete the questionnaire themselves and in their own time. The volunteer was available for assistance if patients had any questions related to the content of the questionnaire. The researcher was also available in case the volunteer was unable to answer their questions.

2.6.1.2 Non-cancer controls

Data collection of the non-cancer controls took place from mid January until the end of January 2007. It was conducted on a daily basis as opposed to the cancer cases where data collection was conducted twice a week only. The reason for these differences in sampling between the two groups was that different weekdays were not linked to specific types of patient groups as was the case with the cancer cases. In terms of record keeping, each dental surgery was provided with a table of how many subjects in each age category needed to be included, to allow for matching according to age and gender. Posters were displayed in the waiting areas to inform subjects of the study in progress. The reception staff identified the patients that were suitable to be included in the study according to their age and gender, and invited them to participate in the study. A letter explaining the purpose of the study and assuring confidentiality (addendum 3) together with an adapted anonymous self-administered questionnaire (addendum 4) were offered at the same time. As patients needed to be matched with the cancer cases, it was not possible to select every third patient that reported to the receptionist, as was the case with the cancer cases. Selection of the controls was discontinued once the required numbers in each age and gender category were obtained. Although there is a slight possibility of introducing bias, it is unlikely that these differences in sampling would have a major impact on the results.

2.6.2 Questionnaire

Self-administered anonymous questionnaires which were compiled by the researcher were used to obtain the required data in the cancer cases, and a similar questionnaire, which was adapted to be suitable for the non-cancer population, was used for the controls. The questionnaire was based on those used in previous CAM studies^{2, 25, 27, 28, 45} which included CAM types most commonly identified in previous studies, reasons for CAM use, notification of health professionals and CAM information sources. However, additional sections relating specifically to diet and nutrition were added (such as dietary changes as a result of cancer, specific micronutrients, and impact on weight).

The content of the questionnaire was validated by a panel of experts (see section 2.6.2.4).

The following information was obtained:

2.6.2.1 *Demographic information:*

- Age
- Gender
- Marital status
- Level of education
- Annual household income

2.6.2.2 *Information relating to diagnosis*

- Type of cancer – tumour site (cases only)
- Time since diagnosis of cancer (cases only)
- Type of treatment e.g. chemotherapy, radiotherapy or hormonal treatment (cases only).
- Other diseases present e.g. diabetes or hypertension.

2.6.2.3 *Information on CAM use*

- Type of CAM use
- Reasons for CAM use
- When CAM was used
- CAM information sources
- Disclosure of CAM use to health professionals
- Reported side effects and benefits
- Satisfaction with CAM use

2.6.2.4 *Questionnaire validity*

In order to ensure content validity of the questionnaires, the input of a panel with clinical and research experience in the field of oncology and the use of CAM therapies among

cancer patients was obtained. The panel consisted of a professor (MD, PhD, FRCP and FRCP (Edin)) from the Department of Complementary Medicine at the Peninsula Medical School in Exeter, a senior lecturer (AFBPsS, MRSS) in Psychology at the University of Wales with an interest in CAM research and a consultant oncology dietitian (PhD) from the Royal Marsden Hospital (London). Recommendations from the panel were mostly related to the manner of phrasing and wording of questions, rather than its content. All recommendations were considered and the questionnaire adjusted accordingly.

Face validity was evaluated by means of a pilot study of ten subjects to assess to what extent the questionnaire was understood by subjects. Five subjects were cancer patients, and the other five were non-cancer patients. Both groups consisted of a convenience sample where the receptionists identified subjects who meet the selection criteria to participate in the study. The pilot study for the cancer cases took place in the Colney Cancer Centre on 25th of October 2006, and the healthy controls in Church Street Dental Practice (Attleborough) on 5th of November 2006. These ten subjects included both gender groups, a variety of age groups, tumour sites, and cancer treatments and were excluded from the final study population. All ambiguous questions identified during the pilot study were subsequently rephrased and clarified according to the responses and suggestions received by the pilot study participants. These changes related to the wording and phrasing of questions, rather than the content of the questionnaire.

2.6.3 Data collection

To increase accuracy, all participants recorded their responses directly onto the questionnaire. Completed questionnaires were collected by the researcher for coding and analysis at the end of data collection. A daily record was kept including the amount of questionnaires handed out at each session, how many were returned on the day, and how many questionnaires were taken home by participants with the intention of completing it at home. Prepaid addressed envelopes were handed out to those participants who chose to complete the questionnaires at home. A record was kept of the number of participants who declined to take part in the study. The researcher

checked the questionnaires for completeness before it was entered into the Excel Spreadsheet. Questionnaires of which only the demographic data were completed were excluded from the study (cancer cases: n=3; non-cancer controls: n=3) Questionnaires that were completed by patients not eligible to participate in the study were also excluded (cancer cases: n=1; non-cancer controls: n=1). All other questionnaires were included for analysis.

2.7 Ethical Issues

The study obtained ethics approval from the Institutional Review Boards of the University of Stellenbosch (project number: N05/10/178), the East Norfolk and Waveney Research Governance Committee (reference number: 2005DIET01S) and the Norfolk (1) Research Ethics Committee (REC Reference number: 06/Q0101/65). Confidentiality of the study population was maintained by the use of anonymous self-administered questionnaires. Patients received a covering letter together with the questionnaire, explaining the purpose of the study, the right to withdraw, what is expected of them, potential benefits / risks, anonymity and confidentiality of information, as well as contact details of the investigator. Consent was assumed if a participant completed and returned the questionnaire. They were not asked to give explanations if they declined to participate in the study and were allowed to withdraw at any time.

2.8 Analysis of Data

The researcher carried out data management by entering the data obtained from the questionnaires into an Excel spreadsheet. Data analysis was performed with the help of a statistician, using Statistica 7 software.

Descriptive statistics were obtained to summarise the means and standard deviations of each variable. Graphs were generated to show the relationship between different variables. To determine whether the data acquired was consistent with a normal distribution, histograms, box plots, Q-Q plots and mean/median values were used to ensure most of the data conformed to a normal distribution. Due to the large number of variables, it was expected that a few of the variables may not be normally distributed. Non-parametric statistics were used where this was not the case.

Homogeneity of variances was considered, before independent sample *T*-tests were undertaken, whilst Mann-Whitney tests were done when data was not normally distributed. To test whether there was a statistically significant difference between the two groups of nominal variables, Chi-square tests were used.

The following data were obtained and analysed:

- Frequency of CAM use among both cancer patients and controls
- The association between CAM use in cancer patients and demographic characteristics
- The most common form of CAM used
- The prevalence of reporting CAM use to health professionals
- The reasons for CAM use
- The perceived side effects/complications of CAM use
- Any differences in the prevalence of CAM use between cancer patients and controls.

CHAPTER 3: RESULTS REPORTING

3.1 Data Collection

3.1.1 Cancer cases

Anonymous questionnaires were offered to a total of 132 cancer patients of which 102 were returned. This gave a response rate of 77.3%. Sixteen patients declined to take part in the study, and 14 of the questionnaires that were handed out were not returned. Of the 102 returned questionnaires, 98 were suitable for analysis. Among the four questionnaires that were not suitable for analysis, one patient did not have cancer, and was therefore excluded. Only the section on demographic information was completed on the remaining three questionnaires and these questionnaires were also excluded from the study.

3.1.2 Non-cancer controls

Anonymous questionnaires were offered to a total of 126 patients of which 96 questionnaires were returned. This gave a response rate of 76.2%. Eleven patients declined to take part in the study, and 19 questionnaires that were handed out, were not returned. Of the 96 returned questionnaires, 92 were suitable for analysis. Among the four questionnaires that were not suitable for analysis and therefore excluded, one patient had a diagnosis of cancer, and the remaining three only answered the questions relating to demographic information.

3.2 Demographic and Diagnosis Related Characteristics

Overall, the cancer cases and the non-cancer controls compared well in terms of their socio-demographic profiles, with no significant differences ($p > 0.05$) in any of the variables referred to in Table 3.1.

The majority of the study population consisted of older people with an average age of 62.7 years [Standard Deviation (SD) 10.9] for the cancer cases and 59.7 years (SD 12.9) for the non-cancer controls. Sixty-three percent of the cancer cases and 56% of the non-cancer controls were over the age of 60 at the time of the study. More women than men participated in the study with women accounting for 59% of the cancer cases and 63% of the non-cancer controls. The majority of participants in both groups were

married or lived with a partner (81% of the cancer cases and 68% of the non-cancer controls respectively).

Table 3.1: Respondents' demographic data

Variable	Cancer Cases (n=98) Number (%)	Non-cancer Controls (n=92) Number (%)
Age in years (chi-square test: p=0.437)		
18 – 29	0 (0%)	3 (3%)
30 – 39	1 (1%)	1 (1%)
40 – 49	12 (12%)	11 (12%)
50 – 59	23 (23%)	26 (28%)
60 – 69	35 (36%)	29 (32%)
70 – 79	21 (21%)	19 (21%)
80 – 89	6 (6%)	3 (3%)
Gender (chi-square test: p=0.586)		
Male	40 (41%)	34 (37%)
Female	58 (59%)	58 (63%)
Marital Status (chi-square test: p=0.056)		
Single	8 (8%)	2 (2%)
Married/living together	79 (81%)	63 (68%)
Divorced/Seperated	4 (4%)	8 (9%)
Widowed	7 (7%)	19 (21%)
Education (chi-square test: p=0.191)		
< GCSE*	29 (31%)	37 (43%)
GCSE	27 (29%)	18 (21%)
A levels	11 (12%)	5 (6%)
Further qualification	27 (29%)	26 (30%)
Household income (chi-square test: p=0.224)		
< £12 000	15 (16%)	9 (10%)
£12 000 - £19 999	15 (16%)	26 (30%)
£20 000 - £29 999	17 (19%)	14 (16%)
£30 000 - £39 999	9 (10%)	10 (12%)
> £ 40 000	12 (13%)	13 (15%)
Retired	23 (25%)	14 (16%)

*GCSE: General Certificate of Secondary Education

The majority of subjects from both groups had an educational level of GCSE (General Certificate of Secondary Education) or lower. Over 40% of the cancer cases and 36% of the non-cancer controls completed their A-levels or obtained a further qualification. Regarding income, the cancer subjects were most frequently retired (25%) whilst the

non-cancer controls were mostly (30%) classified in the band 2 income category (£12 000–£19 999).

Among the cancer cases, the average duration from diagnosis of cancer was 24.2 months. Breast cancer (27%) and gastro-intestinal cancer (23%) were the most common tumour sites and the majority of the patients were having chemotherapy (59%) as their conventional treatment (Table 3.2).

Forty three per cent of the cancer cases and 42% of the controls had some form of reported chronic disease, with hypertension being the most prevalent in both groups (at 13 and 15% respectively). There were no significant differences between the two groups ($p>0.05$).

Table 3.2: Description of the cancer cases and non-cancer controls in terms of the presence of disease

Variable	Cancer Cases (n=98) Number (%)	Non-cancer Controls (n=92) Number (%)
Cancer site		
Breast	26 (27%)	N/A
Gastrointestinal	23 (23%)	N/A
Lung	9 (9%)	N/A
Haematological	14 (14%)	N/A
Gynaecological	7 (7%)	N/A
Other	19 (19%)	N/A
Conventional Therapy *		
Radiotherapy	20 (20%)	N/A
Chemotherapy	58 (59%)	N/A
Hormonal therapy	9 (9%)	N/A
Surgery	16 (16%)	N/A
No active treatment	26 (27%)	N/A
Chronic diseases (chi-square test: $p=0.488$)		
Diabetes	5 (5%)	5 (5%)
Heart disease	6 (6%)	1 (1%)
Hypertension	13 (13%)	14 (15%)
Gout/Arthritis	8 (8%)	4 (4%)
Asthma	3 (3%)	9 (10%)
Other	8 (8%)	6 (7%)

*Total percentage exceeds 100% as some patients chose more than one type of conventional therapy.

* *N/A: Not applicable

3.3 The Most Common CAM Therapies Used by Cancer Subjects and Non-cancer Controls

Forty-six (47%) of the cancer cases and 52 (53%) of the non-cancer controls reported to use some form of CAM therapies with no significant statistical difference in CAM use between the two groups ($p=0.673$). Figure 3.1 illustrates the ten most prevalent forms of CAM use among both groups.

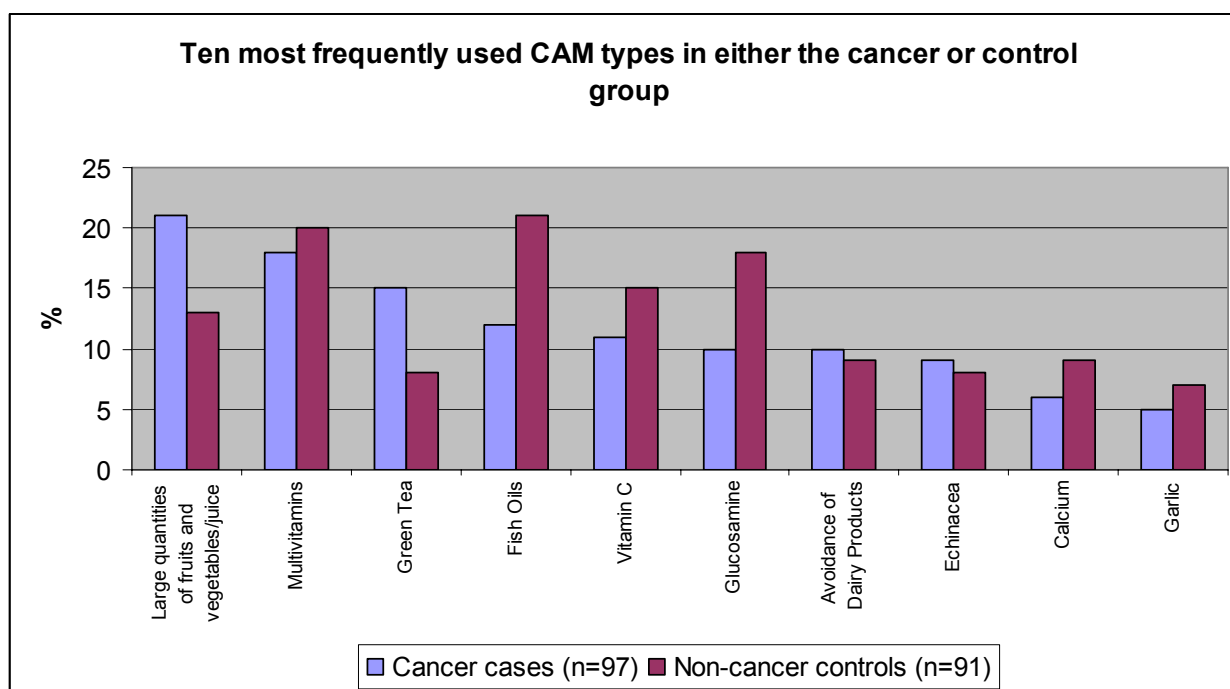


Figure 3.1: Prevalence of dietary related complementary and alternative medicine (CAM) use

The three most common forms of CAM used among the cancer subjects were large quantities of fruit and vegetables/juice (22%), multivitamins (19%) and fish oils (12%) (Table 3.2). In the non-cancer controls, the three most common forms of CAM used were fish oils (23%), multivitamins (22%) and glucosamine (20%). The prevalence of fish oil supplement use among the non-cancer controls was significantly higher than that of the cancer cases ($p=0.045$ with the Chi-square test). Other CAM therapies that were more commonly used included green tea, Echinacea, glucosamine and fish oils. Fifteen per cent of the cancer cases and 9% of the non-cancer controls reported to have used green tea in the past, while 9% of both groups reported to have used Echinacea. Ten per cent of the study population in both groups avoided dairy products.

With the exception of fish oil (see above), prescribed sip feeds ($p=0.028$), beta carotene ($p=0.021$) and selenium ($p=0.004$), there were no significant differences in the use of individual CAM products between the two groups (Table 3.3). Sip feeds, beta carotene and selenium were used to a greater extent by cancer subjects to supplement their oral intake.

Thirty one per cent of cancer patients reported to have used some form of micronutrients in the past in comparison to 41% of the non-cancer controls with no statistical difference between the two groups ($p=0.149$). The most common single vitamin supplement used was vitamin C (11% of cancer patients and 17% of controls respectively) whereas calcium was the most common mineral supplement used (6% of cancer patients and 10% controls). None of these differences were significant ($p>0.05$). Selenium supplements were only used by the cancer patients (6%) with a significant statistical difference between the two groups ($p=0.004$). Alternative medical systems such as the Gerson diet or macrobiotic diet, were not used by either group. Other forms of CAM that were never used by the cancer cases or the non-cancer controls, included shark cartilage and mistletoe. Only 20% of the cancer cases and 16% of the non-cancer controls stated the dose of the supplements taken by them. Due to insufficient numbers that have answered this question, the data could not be analysed further.

To determine whether the presence of chronic diseases influenced the use of CAM in the non-cancer control group, they were split into two further groups, one group with chronic diseases ($n=34$) and the other without any chronic diseases ($n=57$). There was still no significant difference in the use of CAM between any of the groups in comparison to the cancer cases ($p=0.231$ and 0.873 respectively) as determined with the chi-square test ($p=0.231$ and 0.873 respectively).

Table 3.3: Prevalence of dietary related complementary and alternative medicine (CAM) use

Type of CAM	Cancer cases (n=97) Number (%)	Non-cancer controls (n=91) Number (%)	p-value
Multivitamins	18 (19%)	20 (22%)	0.534
Large quantities of fruit and vegetables / juice	21 (22%)	13 (14%)	0.188
Fish Oil	12 (12%)	21 (23%)	0.045
Glucosamine	10 (10%)	18 (20%)	0.058
Vitamin C	11 (11%)	15 (17%)	0.280
Green tea	15 (15%)	8 (9%)	0.159
Avoidance of dairy products	10 (10%)	9 (10%)	0.943
Echinacea	9 (9%)	8 (9%)	0.925
Calcium	6 (6%)	9 (10%)	0.338
Selenium	6 (6%)	0 (0%)	0.004
Garlic	5 (5%)	7 (8%)	0.453
Avoidance of meat	7 (7%)	5 (5%)	0.615
Multivitamins and mineral complex	5 (5%)	5 (6%)	0.903
Vitamin B complex	7 (7%)	3 (3%)	0.231
Other	4 (4%)	5 (6%)	0.695
Vitamin E	7 (7%)	2 (2%)	0.103
Zinc	5 (5%)	3 (3%)	0.526
Use of prescribed sipfeeds	7 (7%)	1 (1%)	0.028
Flaxseed	2 (2%)	3 (3%)	0.582
Other (micronutrients)	4 (4%)	1 (1%)	0.185
Ginko Biloba	2 (2%)	3 (3%)	0.582
Beta Carotene	4 (4%)	0 (0%)	0.021
Milk Thistle	1 (1%)	2 (2%)	0.508
St Johns Wort	1 (1%)	1 (1%)	0.952
Bristol diet	1 (1%)	0 (0%)	0.251
Spirulina	1 (1%)	0 (0%)	0.253
Vitamin A	1 (1%)	0 (0%)	0.249
Ginseng	0 (0%)	1 (1%)	0.224
Lycopene	0 (0%)	1 (1%)	0.226
Gerson diet	0 (0%)	0 (0%)	N/A
Macrobiotic diet	0 (0%)	0 (0%)	N/A
Shark Cartilage	0 (0%)	0 (0%)	N/A
Mistletoe	0 (0%)	0 (0%)	N/A

Fifty-nine per cent (n=20) of the controls with chronic diseases used CAM, whilst 46% (n=26) of the controls without chronic diseases reported to use CAM (Figure 3.2). Although the non-cancer controls with chronic disease had a moderately higher use of CAM in comparison to the cancer cases, there was no statistically significant difference

($p=0.231$) between these two groups. There was also no significant difference in the use of CAM between the cancer cases and non-cancer controls without any chronic diseases ($p=0.873$). Chi-square tests were used to calculate the significance of these differences.

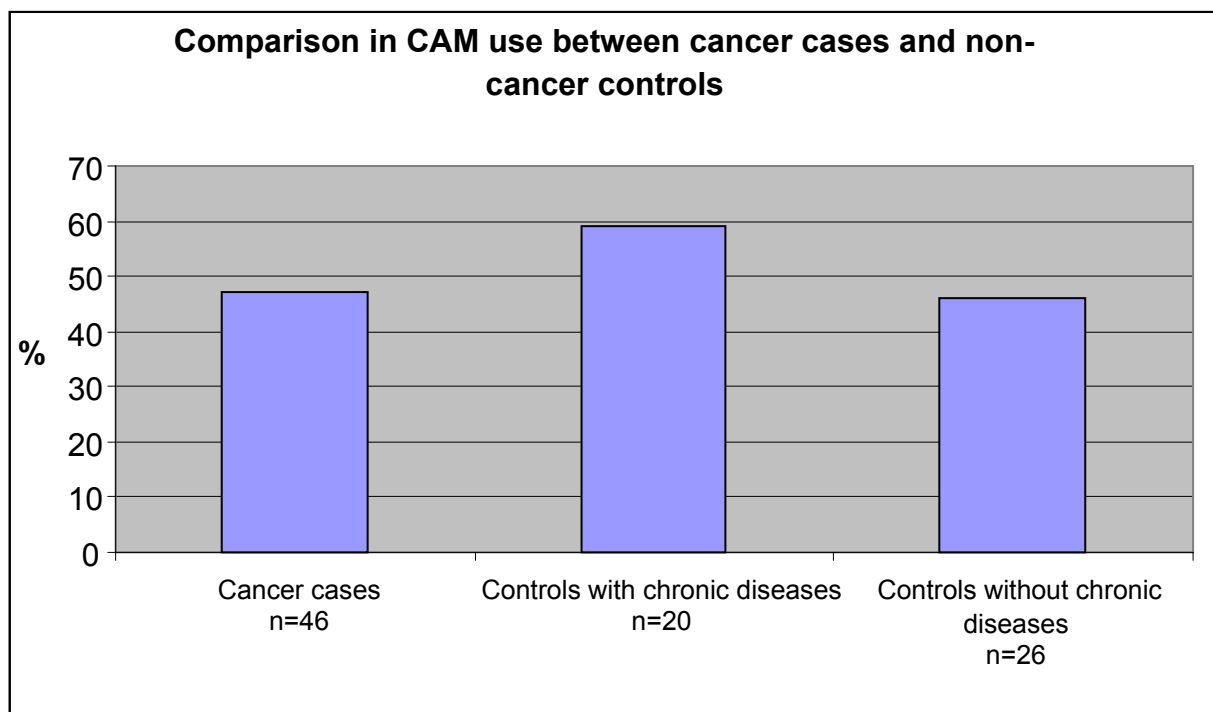


Figure 3.2: Comparison in complementary and alternative medicine (CAM) use between cancer cases and non-cancer controls

3.4 Sociodemographic and Disease Characteristics Associated with CAM

The Mann-Whitney test was used to determine the association between CAM use and characteristics of cancer subjects. Longer duration since diagnosis of cancer ($p=0.050$), and breast cancer ($p=0.036$) were significantly associated with CAM use (Table 3.4). CAM use in cancer subjects was not significantly associated with age, income, level of education, gender, marital status, cancer treatment or the presence of chronic disease.

Similarly, CAM use in the non-cancer controls was also not significantly associated with any of the sociodemographic or disease characteristics ($p>0.05$). In the latter group (non-cancer controls) however, there was a trend of increasing CAM use with increasing educational level ($p=0.08$).

Table 3.4: Sociodemographic and disease characteristics associated with complementary and alternative (CAM) use in cancer patients and non-cancer controls

Variable	Cancer subjects			Non-Cancer controls		
	F-value	M-L Chi-square	P-value	F-value	M-L Chi-square	P-value
Age	0.482	-	0.827	0.047	-	0.829
Level of Income	1.723	-	0.193	0.239	-	0.627
Level of Education	2.098	-	0.151	3.147	-	0.080
Duration since diagnosis	3.936	-	0.050	-	-	N/A
Gender (Male vs female)	-	0.536	0.464	-	0.748	0.387
Marital Status (Single vs Married/Living with a partner vs Widowed vs Divorced)	-	0.395	0.941	-	2.969	0.397
Cancer site Breast Bowel Lung Non-hodgkins lymphoma Leukaemia Colon Bone Other	-	45.279	0.036	-	-	-
Cancer treatment (Yes vs no) Chemotherapy No active treatment Radiotherapy Surgery to remove cancer Hormonal treatment	-	0.102 1.030 0.059 0.072 0.295	0.749 0.310 0.807 0.789 0.587	-	-	-
Presence of additional chronic diseases (yes vs no) Diabetes Heart disease Hypertension Gout Asthma Other	-	1.216	0.270 0.191 0.896 0.618 0.174 0.495 0.555	-	1.493	0.222 0.626 0.241 0.225 0.982 0.699 0.503

* M-L: Maximum likelihood

3.5 Communication with Health Professionals

Of the 46 cancer subjects who reported the use of CAM therapies, only 25 (54%) communicated its use to a health professional (Table 3.5). Even fewer patients from the

control group communicated this to a health professional, namely 23 (44%) of the 52 patients in this group.

Table 3.5 Disclosure of complementary and alternative medicine (CAM) use to health professionals

Health professional informed of CAM use	Cancer patients (n=25) Number (%)	Non-cancer controls (n=23) Number (%)	p-value
Consultant	16 (62%)	6 (26%)	0.116
GP	14 (56%)	14 (61%)	0.732
Nurse	9 (36%)	1 (4%)	0.004
Dietitian	2 (8%)	0 (0%)	0.101
Pharmacist	2 (8%)	2 (9%)	0.931
Other	0 (0%)	1 (4%)	0.222

Table 3.4 indicates that the health professionals who were most frequently informed of CAM use by their patients were consultants and GPs in both groups. With the exception of nurses, there were no significant differences between the two groups. The cancer cases (36%) in this study also tended to inform a nurse of their CAM use significantly more often than the non-cancer controls (4%) with a p-value of 0.004.

3.6 Main Reasons for Using CAM

The majority of subjects from both groups used CAM therapies to boost their immune systems (cancer patients 49%, non-cancer controls 37%) and to improve their quality of life (cancer patients 34%, non-cancer controls 41%) (Table 3.6). Interestingly, significantly more patients from the non-cancer control groups (31%) used CAM therapies to help with pain relief as opposed to the cancer patients (12%) with a p-value of 0.040 (Chi-square test). None of the other differences were significant.

Table 3.6: Main reasons for using complementary and alternative medicine (CAM)

Reasons for using CAM	Cancer patients (n=41) Number (%)	Non-cancer Controls (n=39) Number (%)	p-value
To boost immune system	20 (49%)	14 (37%)	0.283
To improve quality of life	14 (34%)	16 (41%)	0.525
To help with pain relief	5 (12%)	12 (31%)	0.040
Other	6 (15%)	9 (23%)	0.333
To help with stress relief	1 (2%)	2 (5%)	0.524

3.7 Reported Side Effects Associated with CAM Use

Only 2 (5%) of the cancer subjects reported to have experienced side effects from using CAM therapies, and in both cases it was reported to be diarrhoea. It was not possible to state which CAM therapy caused the diarrhoea, as subjects used a range of different therapies. There were no subjects among the non-cancer controls that reported any side effects from these therapies, and there was no significant difference between the two groups ($p=0.106$).

The majority of subjects in both groups reported no change in weight whilst they were using CAM therapies (Figure 3.3). However, the non-cancer controls ($n=39$, 91%) exceeded the cancer cases ($n=22$, 56%) significantly in terms of weight maintenance whilst using CAM (Chi-square test; $p<0.001$). Thirteen per cent ($n=5$) of the cancer cases and 7% ($n=3$) of the non-cancer controls reported to have lost weight whilst using CAM therapies. A further 8% ($n=3$) and 2% ($n=1$) of the cancer cases and controls respectively reported to have gained weight whilst using these therapies.

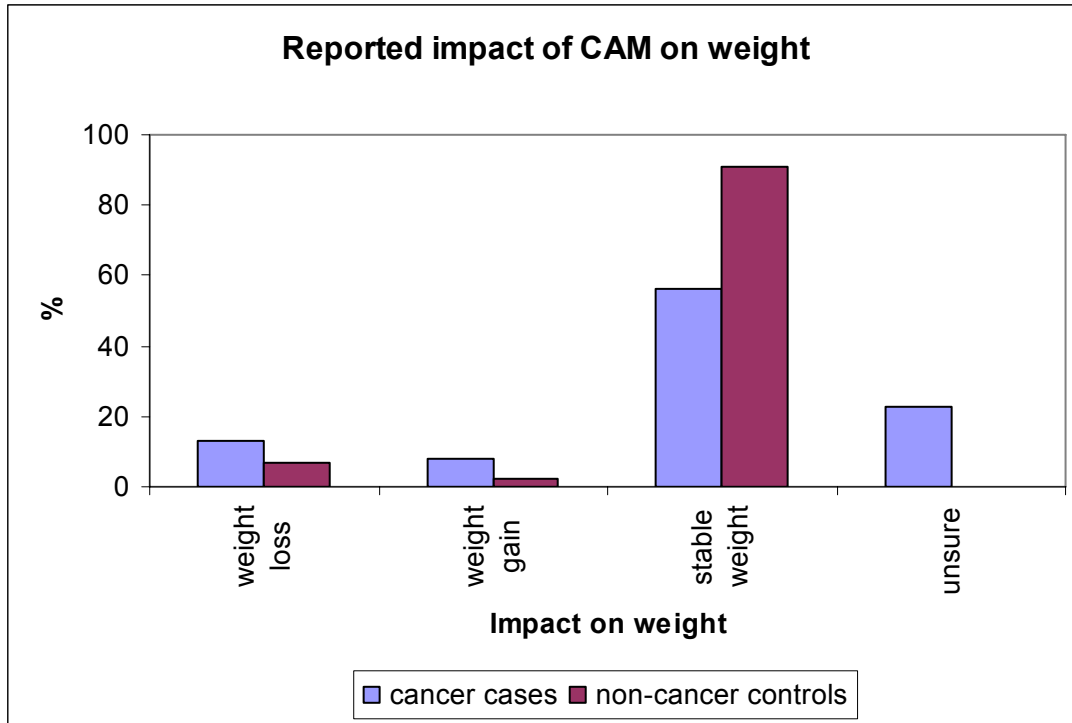


Figure 3.3: Reported impact of complementary and alternative medicine (CAM) use on weight

3.8 Reported Benefits Associated with CAM Use

Overall, the non-cancer controls (n=28; 78%) reported significantly more (p=0.017) benefits as a result of CAM use as compared to the cancer cases (n=19; 51%). In terms of specific benefits (Table 3.7), the cancer cases (47%) reported experiencing optimism as a result of using CAM therapies significantly more often (Chi-square test; p=0.044 compared to the non-cancer controls (20%). There were no other significant differences between the two groups.

Table 3.7: Reported benefits associated with complementary and alternative medicine (CAM) use

Reported benefits	Cancer patients (n=19) Number (%)	Non-cancer Controls (n=30) Number (%)	p-value
Increased optimism	9 (47%)	6 (20%)	0.044
Increased hope	6 (32%)	3 (10%)	0.090
Pain relief	2 (11%)	8 (27%)	0.157
Helped with stress relief	1 (5%)	5 (17%)	0.211
Helped with side effects of cancer treatments	2 (5%)	N/A	N/A
Cured the cancer	0 (0%)	N/A	N/A
Other	6 (32%)	13 (42%)	0.461

*percentages exceed 100%, as participants were allowed to choose more than one option

Nineteen participants reported other benefits from CAM use not specified on the questionnaire. These benefits included increased well-being (8% of non-cancer controls), less pain in joints (4% of non-cancer controls), improved immunity (4% of non-cancer controls), less frequent episodes of cystitis (2% of non-cancer controls), reduced eczema (2% of non-cancer controls), healthier hair (2% of non-cancer controls), faster recovery from colds (2% of non-cancer controls) and increased libido (2% of non-cancer controls). Not all participants, especially the cancer cases, specified which other benefits they experienced.

3.9 Satisfaction with CAM Use

Thirty-nine cancer participants answered the question whether they were satisfied with the CAM therapies they used. Thirty-five of them (90%) reported to be satisfied with it. Similarly, 37 participants among the non-cancer controls answered the above question, and 35 (95%) reported to be satisfied with the CAM therapies they used. There were no statistical difference between the two groups ($p=0.428$, Chi-square test).

3.10 Initial Informant of CAM

Participants were asked who initially informed or encouraged them to use CAM therapies (Table 3.8). The majority of participants in both groups initiated the use of CAM therapies themselves, with a total of 60% in the cancer group and 46% in the

control group. Forty-one per cent of the non-cancer controls were encouraged by their friends or family to try CAM therapies, which was significantly more than just 20% of cancer cases ($p=0.041$, Chi-square test). With the exception of the latter group of informants, there were no significant differences between the two groups.

Table 3.8: Initial informant of Complementary and Alternative Medicine (CAM)

Source of recommendation	Cancer cases (n=41) Number (%)	Non-cancer controls (n=39) Number (%)	p-value
Nurse	0 (0%)	1 (3%)	0.228
General Practitioner	1 (2%)	4 (10%)	0.137
Dietitian	2 (5%)	0 (0%)	0.099
Alternative Therapist	5 (13%)	7 (18%)	0.499
Friends/Family	8 (20%)	16 (41%)	0.041
Self	24 (60%)	18 (46%)	0.217

3.11 Reference used for further information on CAM therapies

Participants were asked how they obtained further information on CAM therapies, once they had been informed or encouraged to use it. Most cancer subjects obtained their information on CAM use from the media (29%), NHS health professionals (25%) and from their friends and family (24%) (Table 3.9). Although the majority of the non-cancer controls also obtained their information from their friends and family (44%) they did so statistically significantly more often than the cancer cases ($p=0.030$). The media was also a popular source of information among the non-cancer controls (33%). NHS health professionals did not feature as prominent in this group (7%), with a statistically significant difference ($p=0.034$) between the two groups as per chi-square test. There were no other significant differences between the two groups.

Table 3.9: Reference used to obtain further information on complementary and alternative medicine (CAM)

Source of information	Cancer cases (n=40) Number (%)	Non-cancer Controls (n=39) Number (%)	p-value
Media	12 (29%)	13 (33%)	0.695
NHS Health professional	10 (25%)	3 (7%)	0.034
Friends/Family	10 (24%)	17 (44%)	0.030
Internet	4 (10%)	4 (10%)	0.970
Other	4 (10%)	6 (15%)	0.446
Alternative health practitioner	3 (8%)	2 (5%)	0.664
Neighbours	2 (5%)	1 (3%)	0.582

CHAPTER 4: DISCUSSION

4.1 Introduction

Cancer patients have been documented to use complementary and alternative medicine (CAM) frequently, but the usage rate varies widely between countries and is based on varying definitions of CAM.^{1, 2, 25} However, the use of CAM is increasing worldwide, and it is important for the health professional working in oncology to be aware of the types of CAM most commonly used in their area, to enable the giving of sound advice in a patient-centred environment. There is a lack in the current literature of controlled studies that investigate the prevalence of CAM use among cancer patients. To the best of our knowledge there is only one such study where the use of CAM in cancer survivors was compared with a non-cancer population.³⁰ According to their findings CAM use was modestly higher among cancer survivors (40%) compared to the general population (36%).

4.2 Discussion of the Results

4.2.1 Comparison of CAM use between cancer cases and non-cancer controls

Our results indicated that there was no significant difference in the overall use of CAM between cancer patients and the non-cancer population, with the non-cancer controls having a marginally higher use (52%) of CAM than the cancer patients (47%). This may have important implications, and shows that an increased awareness and knowledge of CAM use should not be limited to those working with oncology patients only, but be extended to health professionals in all patient groups. Our findings are in contrast with those of Mao et al.³⁰ who found that CAM use was modestly higher among cancer survivors (40%) compared to the general population (36%). However, when the non-cancer controls were split into two groups, (one group with chronic diseases and one group *without* any chronic diseases), the prevalence of CAM use among cancer patients (47%) and non-cancer controls without any chronic diseases (46%) were virtually the same, whereas the non-cancer control group *with* chronic diseases (59%), were moderately higher, although this was not a statistically significant difference. This suggests that the presence of a chronic disease (apart from cancer) may be associated with a modest increase in CAM use.

Looking at the cancer arm of our study population specifically, the prevalence of CAM use (47%) was higher than reported by Downer et al. in 1994 who found that 16% of cancer patients surveyed in two hospitals in London admitted to using CAM.⁹ Our findings were also higher than a recent survey in the UK (2005), which reported that 29% of their sampled cancer population was using some form of CAM.³² However, research has shown that there has been an increase in CAM use among cancer patients in recent years.⁶ Possible explanations may include an increased awareness of CAM therapies among cancer patients, as well as an increased availability of these therapies, especially over the counter remedies and supplements. Our results were similar to the findings of Chrystel et al. (2003) who found that 49% of cancer patients in a New Zealand based cancer centre used CAM.²⁷ It was also consistent with the reported 49% CAM use among colorectal cancer patients in a Canadian based cancer centre in 2002, as well as the findings of Harris et al. (2003) who reported that 49.6% of oncology patients had used at least one type of CAM in the previous 12 months at the time the study was conducted.^{11,25} Our findings were within Ernest and Cassileth's (1998) reported range of 7–64%, based on the results of a systematic review of 21 studies among cancer patients across 13 countries, but higher than their average of 31%.⁶ Clearly there are inconsistencies in the literature with regards to the prevalence of CAM use among cancer patients, which may be attributed to varying definitions of CAM as well as differences in sample selections and instruments used, which limit a direct comparison between these findings.

It therefore appears that CAM use is increasing in the cancer population, as well as in the general population, especially among those with chronic diseases. This may have important implications for health professionals in all patient groups, but especially for those working with cancer patients or patients with other chronic diseases, as certain CAM may interfere with conventional treatment or have undesirable side-effects.

4.2.2 The most popular CAM therapies used among both the cancer cases and non-cancer controls

In terms of the most popular CAM therapies used among both groups, our results indicated that the preferred therapies were very similar in both groups. Large quantities

of juice, multivitamins and fish oils were the three most popular CAM therapies used among the cancer cases, while fish oils, multivitamins and glucosamine were the three most popular CAM therapies used among the non-cancer controls. Interestingly, the prevalence of fish oil supplements among the non-cancer controls was significantly higher than that of the cancer cases, even though fish oils, especially omega-3 fatty acids are often advocated for use in cancer patients. Omega-3 fatty acids and fish oil have been shown to lower the levels of pro-inflammatory cytokines in healthy volunteers and in patients with pancreatic cancer.³³ A fairly recent study has also shown that a fish oil enriched nutritional supplement providing eicosapentaenoic acid (EPA) at 2g per day in combination with protein/energy supplementation can reverse the normal pattern of ongoing weight loss seen in pancreatic cancer patients.³³ On the other hand, fish oil may be better known for its use for other clinical conditions such as rheumatoid arthritis and hypertriglyceridemia,³⁴ and may account for the higher use of fish oils in the non-cancer control group.

Although the use of selenium and β -carotene was low in the cancer group, it was used significantly more than the non-cancer controls. Previous studies have shown that selenium supplementation during chemotherapy offered significant protection from nephrotoxicity induced by the chemotherapy agent, cisplatin.³⁵ It was also associated with less leucopenia and the need for blood transfusions. β -carotene has been shown to enhance the cytotoxicity of some chemotherapy agents on human squamous carcinoma cells.³⁵⁴ These positive effects might explain the higher use of selenium and β -carotene in the cancer group. Of concern, however, is the findings of an increased risk of lung cancer associated with supplementation with β -carotene mentioned previously.²¹

The use of micronutrient supplementation proved to be popular in both groups, with approximately a third (31%) of cancer patients and 41% of the non-cancer controls reported to have used such supplementation at some stage. This was lower than the 48% reported rate by Tough et al. (2002) among Canadian colorectal patients and much lower than the 82.5% reported rate among American cancer patients by Bernstein and Grasso in 2001.^{25, 28} Although the use of micronutrients was fairly high among our British

sample, it appears to be lower than those in the United States and Canada. The doses of the supplements used in our study were not known by the majority of patients, which is of particular concern, as high doses of certain supplements may be toxic. Vitamin A for example can cause acute symptoms such as nausea and vomiting, increased cerebrospinal fluid pressure, muscular incoordination and blurred vision at toxic doses, which in the long-term, can lead to reduced bone mineral density and hepatic dysfunction. Patients with severe protein malnutrition and pre-existing liver disease, both of which are prevalent among oncology patients, are more susceptible to the adverse effects of excess Vitamin A.³⁶ Further research is therefore needed to determine the typical dose of supplements used by cancer patients.

Alternative diets and therapies that claim to cure cancer such as the Gerson diet, Macrobiotic diet, and shark cartilage, were not used by any of the cancer patients or controls in this study population. This can perhaps be explained by the fact that only patients from a conventional treatment cancer centre who were under direct medical treatment was included in this study. The use of alternative therapies in the general cancer population might therefore be higher as indicated by this study. This may account for our general finding that non-cancer controls had a higher CAM use than the cancer cases, although according to an estimate by McGinnis (1990) only a small minority (5%) of cancer patients rejects conventional medicine completely and goes their own way.³⁷ However, as by far the majority of previous CAM related studies in cancer patients only included samples from conventional treatment centres and hospitals, it highlights the need for further research which would include samples from non-conventional cancer centres, i.e. waiting rooms of alternative health practitioners or cancer centres such as the Bristol Cancer Centre. This will provide more accurate information on the prevalence of CAM use in the cancer population as a whole.

4.2.3 Predictors of CAM use

Many studies have looked at the predictors of CAM use and found younger age, female sex, and higher education positively associated with greater CAM use.^{3, 4, 11, 22, 38} In this study time since diagnosis of cancer, and cancer site, were the only significant

demographic variables associated with CAM use. Level of education had a borderline significant association ($p=0.080$) with CAM use among the non-cancer controls only.

4.2.4 Disclosure of CAM use to health professionals

Only 54% of participants disclosed the use of CAM to health professionals. This is consistent with previous studies which found that just about half of the cancer patients who used CAM inform their doctors of such use.^{7, 23, 27} This lack of communication between patients and health professionals may limit the opportunity to discuss the potential benefits and risks of CAM use, which may otherwise enable them to make more informed choices. Although disclosure of CAM use to dietitians was low in particular, they may, as the recognised experts in diet and nutrition, play an important role in providing safe advice on these therapies. In fact, a number of dietitians already practice CAM, while others have established relationships with CAM practitioners.³⁹ Many CAM therapies are safe and may alleviate symptoms associated with cancer or increase patient well-being, on the other hand there are other therapies that may interfere with conventional treatments or have serious side effects. To include direct questioning about CAM use as part of history taking has been shown to significantly increase disclosure of the use of these therapies to the oncologist.⁴⁰ Health professionals working with cancer patients should therefore be encouraged to routinely question patients regarding CAM use, to promote appropriate discussion of these therapies.

4.2.5 Reasons for using CAM therapies

The majority in both groups used CAM therapies to boost their immune systems and to improve their quality of life. Megavitamin supplements are one example of CAM therapies used to boost the immune system. In fact, research has shown that Vitamins A, C, E and β -carotene at high doses stimulate humoral and cellular immunity.⁴¹ Two large nutrition intervention trials conducted in China between 1985 -1991 showed a correlation between dietary supplementation of specific vitamins and minerals and a reduction of the mortality and incidence from human cancer, as well as mortality and prevalence from some other commonly seen diseases.⁴² High doses of vitamin supplementation and diet modification in combination with conventional

radiotherapy/chemotherapy, may also increase tumor response and improve quality of life by decreasing the toxicity of conventional treatment.⁴³

In terms of CAM therapies used to relieve pain, cancer patients used such therapies significantly less than the non-cancer controls. One possible reason may be that CAM therapies intended for pain relieve for other chronic diseases such as gout or arthritis may be more commonly recognized and utilized. A recent study (2007) has shown that glucosamine sulfate caused significant improvement in functional status and pain in patients with osteoarthritis, and is well tolerated.⁴⁴ Another possible explanation for the lower prevalence of CAM therapies for pain relief in the cancer cases may be that cancer patients' pain is usually well controlled with analgesia, which may forfeit the need for additional remedies.

4.2.6 Benefits associated with CAM use

Benefits that were reported among the cancer cases as a result of using CAM therapies included increased optimism (47%) and increased hope (32%). Downer et al. found that hope was the main area of dissatisfaction for the cancer patients in their study population.⁹ This may have important implications for this patient group, as hope appears to be a positive coping strategy which may in turn increase optimism and quality of life. If patients are not encouraged to maintain hope by health professionals, they may seek it from alternative practitioners. It is therefore important for health professionals to address this issue when dealing with cancer patients. This may result in higher levels of satisfaction with conventional care.

4.2.7 Side effects associated with CAM use

Our results indicated that only a small minority of patients experienced side effects as a result of using CAM therapies. Five per cent of the cancer cases reported having experienced diarrhoea and none of the non-cancer controls reported any side effects. This is consistent with the findings of Chrystal et al., who found that 91% of their study population was not aware of any side effects from CAM therapies.²⁷ Gupta et al. (2002) found a slightly higher rate (13%) of minor side effects as a result of CAM use, which included nausea, vomiting, rash and diarrhoea.⁴⁵ Although concerns about side

effects from CAM therapies are often cited in the literature, it appears that it has been reported in only a small minority of patients in previous studies. However, many studies did not ask participants about side effects as a result of their CAM use. Furthermore, patients may not always be aware of the side-effects associated with CAM, as it may be masked by the disease process or the side-effects of conventional treatments. The prevalence of side-effects may therefore be higher as indicated by this study and previous literature, which highlights the need for additional research.

4.2.8 Satisfaction with CAM use

Satisfaction with CAM therapies was high in both groups, with 90% satisfaction rate among the cancer cases, and 95% among the non-cancer controls. Our findings were consistent with that of Downer et al. (1994),⁹ who found that 82% of patients were either satisfied or very satisfied with the therapies they have chosen. The results of our study was higher than those of Begbie et al. (1996)² who reported that 70% of patients in their study were highly satisfied with alternative treatments, while dissatisfaction was almost non-existent (1.4%). Harris et al. (2003)¹¹ also found that 72% of patients in their study was satisfied with CAM (average for all encounters), 4% were dissatisfied and 25% were uncertain. Our results were however much higher than those of Gupta et al. (2002),⁴⁵ who found that only 33% of patients were satisfied with CAM, 57% were dissatisfied and 10% were neutral. The large difference in the latter study may be explained by cultural differences, as it was an Indian population survey, where CAM therapies mostly comprise of ancient systems of healing that are based on concepts of human philosophy.

4.4 Significance of the Study

This is only the second controlled study that we are aware of that investigates the prevalence of CAM use in a cancer population. It is, however, the first controlled study that has looked in depth specifically at dietary related CAM use. Our results indicated that both the cancer cases and non-cancer controls commonly used CAM, and there were no significant differences between the two groups. This shows that an increased awareness and knowledge of CAM use should not be limited to those working with

oncology patients only, but be extended to health professionals in all patient groups. We have shown that disclosure of CAM use to health professionals is low, and patients should therefore be asked directly about their use of CAM, to ensure appropriate discussion of these therapies. Our results also indicated that the two main benefits associated with CAM use were increased optimism and hope, which may be an important coping strategy for patients. It is therefore important for health professionals to encourage patients to have a positive and hopeful attitude. The provision of certain CAM therapies by the NHS in combination with conventional care may be a way forward to meet this need. Certainly, we need to have ready access to reliable patient information regarding such therapies, which may help patients to make safe and informed decisions about their use.

4.5 Limitations

Several limitations were noted in this study.

Firstly, it should be noted that this study targeted patients undergoing conventional cancer treatment. It does therefore not account for patients who substituted conventional care with CAM as their sole treatment. Nevertheless, it does indicate that a significant proportion of cancer patients in the Colney Cancer Center use some form of CAM therapy, and gives some idea of the current range of therapies.

Secondly, the characteristics of the non-responders are not known, as response to the survey was voluntary and anonymous. This may have created a potential selection bias if non-responders overrepresented a particular subgroup. The response rate of the study was however very good.

Thirdly, in terms of calculating an appropriate sample size for the study, the original 5% level of precision at a 95% confidence interval was changed to a 10% level of precision on request from the Norfolk Research Ethics Committee. Consequently, the sample size was reduced from 321 patients in each group, to 92 patients. The concern was raised that the proposed amount of data to be collected may not be needed, and that the study could place an unnecessary burden on a fragile oncology group.

Fourthly, there are also the limitations typical of a questionnaire used as an instrument, which include questions that may be misunderstood, facts wrongly remembered and answers deliberately falsified.

Finally, the study did not control for ethnicity which may have introduced a small degree of bias. However, as only 6% of the Norwich population consists of ethnic minorities (of which 3% is non-white) it was not considered to have a major impact on the results.

CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

5.1 Conclusions

CAM therapies among cancer patients have been extensively researched in uncontrolled studies and their use proven to be high in this patient population. Our study has, however, indicated that the prevalence of CAM among cancer patients is no higher than that of the general population. This shows that an increased awareness and knowledge of CAM use should not be limited to those working with oncology patients only, but be extended to health professionals in all patient groups. Disclosure of CAM use to health professionals was low in this study, which highlights the importance of good communication with cancer patients, including direct questioning of CAM use.

The main reasons for using CAM therapies in both the cancer patients and non-cancer controls were to boost their immune systems and to improve quality of life. Furthermore, we found that increased optimism and hope were the two main benefits reported as a result from using CAM, and may consequently be an important aid to cope with the diagnosis of cancer and the side effects of its conventional treatment. Health professionals should therefore encourage patients to maintain a positive and hopeful attitude throughout their cancer journey. Furthermore is it important to help patients identify those CAM therapies that are likely to benefit them, and to provide greater access to these in the NHS. We also need to have ready access to reliable patient information regarding such therapies, which may help patients to make safe and informed decisions about their cancer care.

Health professionals should also establish good communication and encourage a positive and hopeful attitude in cancer patients, which may result in higher levels of satisfaction with conventional care.

5.2 Recommendations

In light of the findings of this study, we would suggest the following recommendations:

1. Further research is needed on CAM use that includes samples from non-conventional cancer centres i.e. complementary or alternative health care

centres to ensure a more accurate reflection of CAM use in the general cancer population.

2. Side effects of CAM use should be more extensively researched, in order for health professionals to give safe advice on the use of these therapies.
3. Further research is also needed on the frequency and dose of supplements taken, to ensure the safe use of CAM therapies.

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APPENDICES

Addendum 1

Norfolk and Norwich University Hospital NHS Trust

PATIENT INFORMATION SHEET (COLNEY CENTRE)

STUDY TITLE:

Prevalence and usefulness of dietary related complementary and alternative therapies among cancer patients.

REFERENCE NUMBER: 2005DIET01S

You are being invited to take part in a research study. Before you decide to take part in the study it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

- Part 1 tells you the purpose of this study and what will happen if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

PART 1

What is the purpose of the study?

The purpose of the study is to find out how many patients with cancer make use of dietary related therapies (other than the conventional medical treatments) to help with their cancer. We would also like to know if cancer patients are more likely to use such therapies than the general healthy population. At present there is not enough information available in the United Kingdom to give us a clear picture. If we have a better understanding of the general trend and which dietary therapies are more popular to use, it will help health professionals to offer advice to patients who wish to discuss or ask about such therapies. This study forms part of a student research project which forms part of the study requirements of a Masters Degree in Nutrition

Why have I been chosen

We aim to ask every patient with cancer attending the Colney Centre to participate in the study until we have recruited 92 patients. We hope to include 92 patients in the Colney Centre and the same number of healthy participants in 3 selected dental surgeries.

Do I have to take part?

No. It is up to you if you decide whether or not to take part. If you do, you will be

given this information sheet to keep. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen if I take part?

The volunteer will offer you a questionnaire to complete. If you have read all the information on the patient information sheet, and decided that you wish to take part, you can either complete the questionnaire at the Colney Centre and give it back to a volunteer, or put it in the purple box at reception. If you did not have enough time to complete the questionnaire in the Colney Centre today, or you need more time to decide whether you want to take part in this study, please feel free to take the questionnaire home with you. A pre-paid envelope is available from reception which could be used to return completed questionnaires in.

The questionnaire may take you approximately 20 – 25 minutes to complete.

What do I have to do?

Please complete one questionnaire only and place it in the envelope provided, before returning it to us. Please ask the volunteer for assistance if you require any help to complete the questionnaire. Please do not fill in this questionnaire if you already completed this questionnaire before.

What are the benefits of taking part?

The study may not benefit you directly, but the information we get might help improve the service for patients with cancer.

What if there is a problem?

Any complaint about the way that you have been dealt with during the study will be addressed. Please contact the researcher (Esmarie van Tonder) on 01603-287 011 if you wish to discuss any complaints regarding this study.

Will my taking part in the study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential.

Is there any thing else that you should know or do?

The questionnaire includes questions relating to your demographical characteristics, i.e. age, gender, income and education level, which will help us to find out whether certain characteristics are more closely linked to certain dietary patterns than others. If there is one or more question(s) that you are unwilling or feel uncomfortable to give an answer to, you may leave that question(s) out.

Contact details of the principal investigator:

Esmarie van Tonder

ADDRESS:

Department of Nutrition and Dietetics
Level 4, Out-patients East
Norfolk and Norwich University Hospital

CONTACT NUMBER: 01603 287011

This completes part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?

You may withdraw from the study at any time. However, once we have received the completed questionnaire back from you, it will not be possible to withdraw the information provided, from the study.

What if there is a problem?

If you have a concern about this study, you should ask to speak with the researcher who will do her best to answer your questions (Tel: 01603 287 011). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints procedure. Details can be obtained from the Hospital.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. As the questionnaire is anonymous, no one will be able to identify you as a person. The information obtained during the study will be stored with the researcher for a period of 5 years. Only the researcher, the study leader and a statistician will have access to the information.

What will happen to the results of the research study?

The results may be published in a medical journal. A summary sheet of the results will also be made available in the Colney Centre.

Who is organizing and funding the research?

The researcher will pay for all costs involved in the study.

Who has reviewed this study?

The study was given a favorable opinion for conduct in the NHS by the Norfolk (1) Research Ethics Committee.

Thank you for your consideration to take part in this study, and for taking the time to read through this sheet.

Addendum 2

Norfolk and Norwich University Hospital



NHS Trust

Patient Questionnaire (Colney Centre)

Prevalence and Usefulness of Dietary Related Complementary and Alternative therapies among cancer patients

1. What is your age in years?

.....

2. Gender

a) ☐ Male b) ☐ Female

3. Marital status

a) ☐ Single b) ☐ Married/Living with a partner
c) ☐ Divorced/Seperated d) ☐ Widowed

4. What is your highest level of education?

a) ☐ No GCSE or equivalent b) ☐ GCSE or equivalent
c) ☐ A levels d) ☐ Further qualification

5. What is your household income (per year)?

a) ☐ Less than £12 000 b) ☐ £12 000 – £19 999 c) ☐ £20 000 – £29 999
d) ☐ £30 000 – £39 999 e) ☐ >£40 000 f) ☐ Retired

6. What type of cancer do you have?

.....

7. How long ago have you been told that you have cancer?

.....

8 i) Do you have any other chronic (long standing) illness at present?

a) ☐ Yes

b) ☐ No

8 ii) If yes, please indicate which of the following illnesses you have:

a) ☐ Diabetes

b) ☐ Heart disease

c) ☐ High blood pressure

d) ☐ Gout/Arthritis

e) ☐ Asthma

f) ☐ Other (please specify).....

9. Regarding your medical cancer treatment

What type of cancer treatment are you currently having (tick all that applies)?

a) ☐ Radiotherapy

b) ☐ Chemotherapy

c) ☐ Hormonal therapy

d) ☐ Operation to remove the cancer

e) ☐ No active treatment

10. Prescribed Nutritional Supplements

Do you currently take any milkshake/fruit juice-style nutritional supplements (e.g. Ensure Plus, Enlive Plus, Fortisip, Scandishake, Calogen) to increase the calorie and protein content of your diet?

a) ☐ Yes

b) ☐ No

If your answer is yes, please specify the name(s) of the milkshake/fruit juice style supplement you are currently taking

.....

REGARDING YOUR CURRENT CANCER ILLNESS AND DIETARY HABITS:

11.1) Have you used any other dietary therapies or supplements during the past 6 weeks (other than referred to in question 10)?

- a) ☐ Yes b) ☐ No

11.2) If your answer is no, please give your main reason:

- a) ☐ Additional costs
- b) ☐ Too time consuming to fit it in your daily schedule
- c) ☐ Other (please specify reason)

12. Have you as a result of your cancer changed your diet in any of the following ways?

- a) Avoidance of meat Yes ☐ No ☐
- b) Avoidance of dairy products Yes ☐ No ☐
- c) Use of high amounts of fruit and vegetable / juices Yes ☐ No ☐
- d) ☐ Other changes to your diet (please specify)

13. Have you in the past used or are you currently following any of the following diets, as a result of your cancer?

- a) Gerson diet Yes ☐ No ☐
- b) The Macrobiotic diet Yes ☐ No ☐
- d) The Bristol diet Yes ☐ No ☐
- e) ☐ Other (please specify).....

14.1) Have you used any vitamin or mineral supplements since your diagnosis of cancer?

- a) ☐ Yes b) ☐ No

14.2) If yes, which of the following vitamin or mineral preparations have you used?

- a) Multivitamins Yes ☐ No ☐
- b) Multivitamin and mineral complex Yes ☐ No ☐
- c) Vitamin C Yes ☐ No ☐ Daily Dose
- d) Vitamin E Yes ☐ No ☐ Daily Dose.....
- e) Vitamin B complex Yes ☐ No ☐ Daily Dose.....
- f) Vitamin A Yes ☐ No ☐ Daily Dose.....
- g) Beta Carotene Yes ☐ No ☐ Daily Dose.....
- h) Lycopene Yes ☐ No ☐ Daily Dose.....
- i) Calcium Yes ☐ No ☐ Daily Dose.. ..
- j) Selenium Yes ☐ No ☐ Daily Dose.....
- k) Zinc Yes ☐ No ☐ Daily Dose.....
- l) ☐ Other (please specify).....

15. Please indicate if you have used any of the following since your diagnosis of cancer and indicate for how long:

- a) Green Tea Yes ☐ No ☐ Number of years.....
- b) Grape seed Yes ☐ No ☐ Number of years.....
- c) Echinacea Yes ☐ No ☐ Number of years.....
- d) Chaparral Yes ☐ No ☐ Number of years.....
- e) Flaxseed Yes ☐ No ☐ Number of years.....
- f) Mistletoe (Isador) Yes ☐ No ☐ Number of years.....
- g) Shark cartilage Yes ☐ No ☐ Number of years.....
- h) Milk Thistle Yes ☐ No ☐ Number of years.....

- | | | | |
|---|------------------------------|-----------------------------|----------------------|
| i) Glucosamine | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Number of years..... |
| j) Fish oil | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Number of years..... |
| k) Garlic pills | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Number of years..... |
| l) Ginko Biloba | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Number of years..... |
| n) Ginseng | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Number of years..... |
| o) St John's Wort | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Number of years..... |
| p) Spirulina | Yes <input type="checkbox"/> | No <input type="checkbox"/> | Number of years..... |
| q) <input type="checkbox"/> Other (please specify)..... | | | |

Please only complete the rest of the questionnaire if you answered "yes" to any of questions 11 - 15

16. Did you find any difference in your weight whilst being on these therapies/diets?

- a) ☐ Weight loss b) ☐ Weight gain c) ☐ No change in weight
- d) ☐ Not sure

17. Who initially recommended to you to use any of these therapies/diets?

- a) ☐ Consultant Oncologist b) ☐ Nurse specialist c) ☐ GP
- d) ☐ Dietitian e) ☐ Alternative therapist f) ☐ Pharmacist
- g) ☐ Friends/Family h) ☐ Self

18. Where did you obtain information about these therapies?

- a) ☐ NHS Health professional b) ☐ Alternative health practitioner
- c) ☐ Internet d) ☐ Friends/Family
- e) ☐ Media (Newspaper/Television/Magazine) f) ☐ Neighbors

g) ☐ Other (please specify)

19. What is (or was) your main reason to use these therapies (tick one only)?

a) ☐ To help with side effects of cancer treatments

b) ☐ For pain relief

c) ☐ To boost your immune system

d) ☐ To improve your quality of life

e) ☐ To help stress relieve

f) ☐ Hope it has an anti-cancer effect

g) ☐ Hope it can cure the cancer

h) ☐ Other (please specify)

20.1) Did you inform any health professional that you are using any of these complimentary therapies/remedies?

a) ☐ Yes

b) ☐ No

If your answer is no, please explain why you did not tell anyone

.....

20.2) If yes, please specify whom you told

a) Consultant Yes ☐ No ☐

b) GP Yes ☐ No ☐

c) Specialist Nurse Yes ☐ No ☐

d) Dietitian Yes ☐ No ☐

e) Pharmacist Yes ☐ No ☐

f) ☐ Other (please specify).....

21. Did you experience any side effects from the dietary therapies or supplements you have used?

a) ☐ Yes

b) ☐ No

If your answer is yes, please specify which side effects you experienced:

.....

22.1 Did you experience any benefits from using dietary therapies/ supplements?

a) ☐ Yes

b) ☐ No

22.2 If your answer is yes, please specify which of the following benefits you experienced:

a) ☐ Helped with side effects of cancer treatments

b) ☐ Pain relief

c) ☐ Helped with stress relieve

d) ☐ Increased your hope

e) ☐ It cured the cancer

f) ☐ Increased optimism/positive thinking

g) ☐ Other (please specify)

23. Were you satisfied with the dietary therapy/supplements that you have used?

☐ Yes

☐ No

If no, please specify why you were not satisfied

.....

Thank you for taking the time to complete the questionnaire. Please put the questionnaire in the box provided at reception.

Researcher:

Esmarie van Tonder (Senior Dietitian)

Department of Nutrition and Dietetics

Level 4, East Block
Norfolk and Norwich University Hospital NHS Trust
Tel: 01603 287011

Addendum 3



PATIENT INFORMATION SHEET (DENTAL SURGERIES)

STUDY TITLE:

Prevalence and usefulness of dietary related complementary and alternative therapies among cancer patients.

REFERENCE NUMBER: 2005DIET01S

You are being invited to take part in a research study. Before you decide to take part in the study it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

- Part 1 tells you the purpose of this study and what will happen if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

PART 1

What is the purpose of the study?

The purpose of the study is to find out how many patients with cancer make use of dietary related therapies (other than the conventional medical treatments) to help against cancer. We would also like to know if cancer patients are more likely to use such therapies than the general healthy population. At present there is not enough information available in the United Kingdom to give us a clear picture. If we have a better understanding of the general trend and which dietary therapies are more popular to use, it will help health professionals to offer advice to patients who wish to discuss or ask about such therapies. This study forms part of a student research project which forms part of the study requirements of a Masters Degree in Nutrition

Why have I been chosen

This dental surgery forms part of the healthy control part of the study. We aim to ask every patient attending this dental surgery during the period of research, to participate in the study until we have recruited approximately 31 patients from this dental surgery.

Do I have to take part?

No. It is up to you if you decide whether or not to take part. If you do, you will be given this information sheet to keep. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen if I take part?

The receptionist will offer you a questionnaire to complete. If you have read all the information on the patient information sheet, and decided that you wish to take part, you can complete the questionnaire at the dental surgery and give it back to the receptionist. If you did not have enough time to complete the questionnaire in the dental surgery today, or you need more time to decide whether you want to take part in this study, please feel free to take the questionnaire home with you. A pre-paid envelope is available from reception which could be used to return completed questionnaires in.

The questionnaire may take you approximately 20 – 25 minutes to complete.

What do I have to do?

Please complete one questionnaire only and place it in the envelope provided, before returning it to us. Please ask the receptionist for assistance if you require any help to complete the questionnaire. Please do not fill in this questionnaire if you have already completed this questionnaire before.

What are the benefits of taking part?

The study may not benefit you directly, but the information we get might help improve the service for people with cancer.

What if there is a problem?

Any complaint about the way that you have been dealt with during the study will be addressed. Please contact the researcher (Esmarie van Tonder) on 01603-287 011 if you wish to discuss any complaints regarding this study.

Will my taking part in the study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential.

Is there any thing else that you should know or do?

The questionnaire includes questions relating to your demographical characteristics, i.e. age, gender, income and education level, which will help us to find out whether certain characteristics are more closely linked to certain dietary patterns than others. If there is one or more question(s) that you are unwilling or feel uncomfortable to give an answer to, you may leave that question(s) out.

Contact details of the principal investigator:

Esmarie van Tonder

ADDRESS:

Department of Nutrition and Dietetics

Level 4, Out-patients East
Norfolk and Norwich University Hospital
CONTACT NUMBER: 01603 287011

This completes part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in part 2 before making any decision.

PART 2

What will happen if I don't want to carry on with the study?

You may withdraw from the study at any time. However, once we have received the completed questionnaire back from you, it will not be possible to withdraw the information provided, from the study.

What if there is a problem?

If you have a concern about this study, you should ask to speak with the researcher who will do her best to answer your questions (Tel: 01603 287 011).

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. As the questionnaire is anonymous, no one will be able to identify you as a person. The information obtained during the study will be stored with the researcher for a period of 5 years. Only the researcher, the study leader and a statistician will have access to the information.

What will happen to the results of the research study?

The results may be published in a medical journal. A summary sheet of the results will be made available in the dental surgery.

Who is organizing and funding the research?

The researcher will pay for all costs involved in the study.

Who has reviewed this study?

The study was given a favorable opinion for conduct in the NHS by the Norfolk (1) Research Ethics Committee.

Thank you for your consideration to take part in this study, and for taking the time to read through this sheet.

Addendum 4

Norfolk and Norwich University Hospital NHS Trust

Patient Questionnaire (Dental Surgeries)

Prevalence and Usefulness of Dietary Related Complementary and Alternative therapies among cancer patients

1. What is your age in years?

.....

2. Gender

- a) ☐ Male b) ☐ Female

3. Marital status

- a) ☐ Single b) ☐ Married /Living with a partner c) ☐ Divorced/Seperated
d) ☐ Widowed

4. Highest level of education:

- a) ☐ No GCSE or equivalent b) ☐ GCSE or equivalent
c) ☐ A levels d) ☐ Further qualification

5. Household income (per year):

- a) ☐ Less than £12 000 b) ☐ £12 000 – £19 999 c) ☐ £20 000 – £29 999
d) ☐ £30 000 – £39 999 e) ☐ >£40 000 f) ☐ Retired

6.1) Do you have any chronic (long standing) illness at present?

- a) ☐ Yes b) ☐ No

6.2) If yes, please indicate which of the following:

- a) ☐ Diabetes b) ☐ Heart disease c) ☐ High blood pressure
d) ☐ Gout/Arthritis e) ☐ Asthma
f) ☐ Other (please specify).....

7. Prescribed Nutritional Supplements

Do you currently take any milkshake/fruit juice-style nutritional supplements (e.g. Ensure Plus, Enlive Plus, Fortisip, Scandishake, Calogen) to increase the calorie and protein content of your diet?

- a) ☐ Yes b) ☐ No

If your answer is yes, please specify the name of the milkshake/fruit juice style supplement you are currently taking

.....

8.1 Have you used any other dietary therapies or supplements during the past 6 weeks (other than referred to in question 7)?

- a) ☐ Yes b) ☐ No

8.2) If your answer is no, please give your main reason:

- a) ☐ Additional costs
b) ☐ Too time consuming to fit it in your daily schedule
c) ☐ Other (please specify reason)

9. Have you in the past or are you at present modifying your diet in any of the following ways?

- a) Avoidance of meat ☐ Yes ☐ No
b) Avoidance of dairy products ☐ Yes ☐ No

c) Use of high amounts of fruit and vegetable juices ☐ Yes ☐ No

d) Other changes to your diet (please specify)

.....

10. Have you in the past used or are you currently following any of the following diets?

a) Gerson diet Yes ☐ No ☐

b) The Macrobiotic diet Yes ☐ No ☐

d) The Bristol diet Yes ☐ No ☐

e) ☐ Other (please specify).....

11.1) Have you ever used any vitamin or mineral supplements for health reasons?

☐ Yes ☐ No

11.2) If yes, which of the following vitamin or mineral preparations have you used?

a) Multivitamins Yes ☐ No ☐

b) Multivitamin and mineral complex Yes ☐ No ☐

c) Vitamin C Yes ☐ No ☐ Daily Dose

d) Vitamin E Yes ☐ No ☐ Daily Dose.....

e) Vitamin B complex Yes ☐ No ☐ Daily Dose.....

f) Vitamin A Yes ☐ No ☐ Daily Dose.....

g) Beta Carotene Yes ☐ No ☐ Daily Dose.....

h) Lycopene Yes ☐ No ☐ Daily Dose.....

i) Calcium Yes ☐ No ☐ Daily Dose.....

j) Selenium Yes ☐ No ☐ Daily Dose.....

k) Zinc Yes ☐ No ☐ Daily Dose.....

l) ☐ Other (please specify).....

12. Please indicate if you have used any of the following and indicate for how long:

a) Green Tea Yes ☐ No ☐ Number of years.....

b) Grape seed Yes ☐ No ☐ Number of years.....

c) Echinacea Yes ☐ No ☐ Number of years.....

d) Chaparral Yes ☐ No ☐ Number of years.....

e) Flaxseed Yes ☐ No ☐ Number of years.....

f) Mistletoe (Iscador) Yes ☐ No ☐ Number of years.....

g) Shark cartilage Yes ☐ No ☐ Number of years.....

h) Milk Thistle Yes ☐ No ☐ Number of years.....

i) Glucosamine Yes ☐ No ☐ Number of years.....

j) Fish oil Yes ☐ No ☐ Number of years.....

k) Garlic pills Yes ☐ No ☐ Number of years.....

l) Ginko Biloba Yes ☐ No ☐ Number of years.....

n) Giseng Yes ☐ No ☐ Number of years.....

o) St John's Wort Yes ☐ No ☐ Number of years.....

p) Spirulina Yes ☐ No ☐ Number of years.....

q) ☐ Other (please specify).....

Please only complete the rest of the questionnaire if you answered "yes" to any of questions 8 – 12.

13. Did you find any difference in your weight whilst being on these therapies/diets?

- a) ☐ Weight loss b) ☐ Weight gain c) ☐ No change in weight
d) ☐ Not sure

14. Who initially recommended to you to use any of these therapies/diets?

- a) ☐ Nurse specialist b) ☐ GP c) ☐ Dietitian d) ☐ Alternative therapist
e) ☐ Pharmacist f) ☐ Friends/ Family g) ☐ Self

15. Where did you obtain information about these therapies?

- a) ☐ NHS Health professional b) ☐ Alternative health practitioner
c) ☐ Internet d) ☐ Friends/Family
e) ☐ Media (Newspaper/Television/Magazine) f) ☐ Neighbors
g) ☐ Other (please specify)

16. What is (or was) your main reason to use these therapies (tick one only)?

- a) ☐ To boost your immune system
b) ☐ To improve your quality of life
c) ☐ To help stress relieve
d) ☐ To relieve pain
e) ☐ Increased optimism/positive thinking
f) ☐ Other (please specify)

17.1) Did you inform any health professional that you are using any of these complimentary/alternative therapies?

- a) ☐ Yes b) ☐ No

If your answer is no, please specify why not

.....

17.2) If yes, please specify whom you told

a) Consultant Yes ☐ No ☐

b) GP Yes ☐ No ☐

c) Specialist Nurse Yes ☐ No ☐

d) Dietitian Yes ☐ No ☐

e) Pharmacist Yes ☐ No ☐

f) ☐ Other (please specify).....

18.1 Did you experience any side effects from the dietary therapies or supplements you have used?

Yes ☐

No ☐

18.2 If your answer is yes, please specify which side effects you experienced:

.....

19.1 Did you experience any benefits from using complimentary therapies?

a) ☐ Yes

b) ☐ No

19.2 If your answer is yes, please specify which of the following benefits you experienced:

a) ☐ Pain relief

b) ☐ Helped with stress relieve

c) ☐ Increased your hope

d) ☐ Increased optimism/positive thinking

e) ☐ Other (please specify)

20. Were you satisfied with the complimentary therapy (home remedy) that you have used?

a) ☐ Yes

b) ☐ No

If no, please specify why you were not satisfied

.....

Thank you for taking the time to complete the questionnaire. Please put the questionnaire in the envelope provided and hand back to reception.

Researcher:

Esmarie van Tonder (Senior Dietitian)

Department of Nutrition and Dietetics

Level 4, East Block

Norfolk and Norwich University Hospital NHS Trust

Tel: 01603 287011